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Ethical Dimensions of Community Engagement and Involvement in Global Health Research

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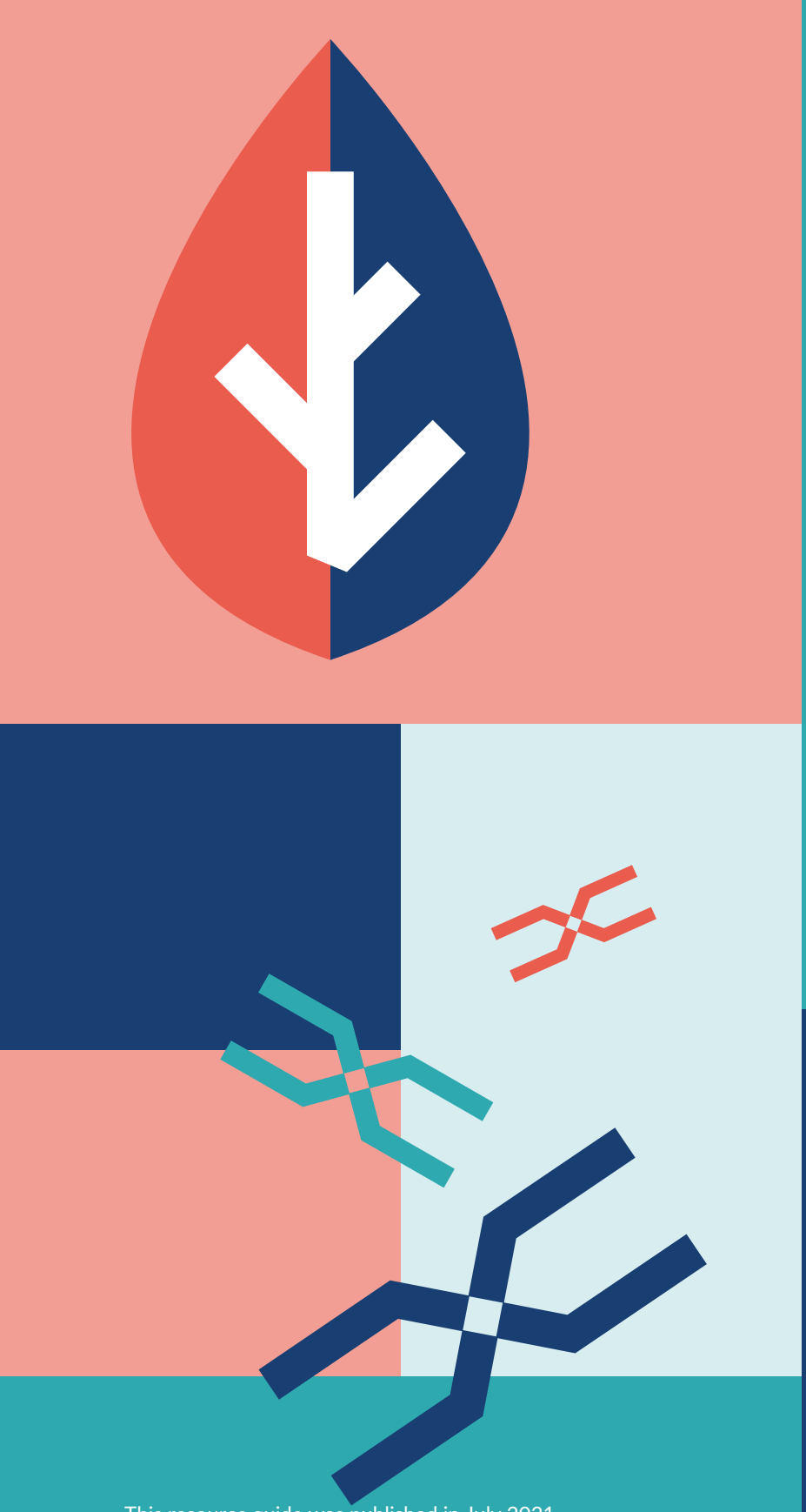

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Front cover image:
Annual review meeting in Sacatepequez Province, Guatemala

Introduction

In this second in a three-part series of National Institute of Health Research (NIHR) Community Engagement and Involvement (CEI), we dive into the topic of ethics. For NIHR's Global Health Research Portfolio, (CEI) is both a means to achieve greater impact, as well as reflective of an institutional commitment to collaborative research. Within global health research broadly speaking, CEI activities may be designed to achieve a range of objectives, ranging from the instrumental to the transformative [1]. This brief does not focus explicitly on formal ethics review processes, but rather on the ethical goals of CEI itself. These ethical dimensions of CEI include: the importance of establishing mutual respect and relationships of trust at community-level; working out appropriate community benefits; engaging in consultative processes to address any concerns related to risks of participation and to inform study design, and building a deeper understanding of how the research interacts with vulnerable and marginalised groups within communities [1, p. 3]. To these established ethical goals we would add social justice and health equity imperatives [2-4].

The first learning event hosted by the Institute of Development Studies and NIHR gave an overview of CEI and its intrinsic value to global health research. In the second event we discussed how to share power in the context of community engaged health research, and what ethical dilemmas have been raised by doing CEI during the Covid-19 pandemic. This text reflects ongoing dialogue between the facilitator (Erica Nelson, IDS) and co-presenters (Bridget Pratt, Australian Catholic University, and Dorcas Kamuya and Noni Mumba, KEMRI Wellcome Trust Research Programme) on how to address the complex dynamics of doing CEI ethically.

Taking a social justice approach to CEI

As viewed through a social justice lens, ethical best practice demands meaningful community engagement and involvement in all stages of global health research. To put it bluntly, individuals and communities should be involved in decisions that affect their lives. This is clearly the case when the research questions being addressed have the potential to contribute to improving access, quality and inclusivity of health services. Such an approach can make explicit what might otherwise be implicit biases that inadvertently or purposively exclude marginalised and minority perspectives. Developing a meaningful CEI approach is not without its challenges. What follows captures a few key issues raised by the recently launched Research for Health Justice framework and toolkit [5].

How will you create spaces and sites for engagement that enable power-sharing?

A practical entry point is to start with the question of space – e.g the physical sites or virtual platforms where community engagement will take place. ***How will you or your team identify potential spaces and sites of engagement and co-leadership?*** It is important to recognise that global health research is typically an "invited space" in practice [6]. In the simplest terms, this means that people with more power often "invite" those with less power into what would otherwise be a "closed" space: the research enterprise. In practice, this might mean foreign and/or national researchers invite locally-based researchers or community organisations to collaborate on a research project. It could entail inviting community members to a local health clinic or the offices of an academic research institution for the purposes of running a focus group discussion or carrying out face-to-face interviews. The community organisations/members enter into the space on the academic research team's terms, and so contribute further to the unequal power dynamics between community members/participants on the one hand and researchers on the other. Two types of power dynamics are then often recreated within such spaces—namely, those of 'expert' academic researchers over community organisations and 'lay' citizens and those of foreign researchers from high-income countries over researchers from low and middle-income countries (LMICs). This stands in contrast to "created" spaces that emerge organically and over which community organisations and community members have greater ownership. In these spaces, the research team is the "invitee" and thus in the position of having to understand the dynamics and norms that govern this "created space". If the researcher is embedded within the community that is being engaged and involved, they will be better able to identify already existing "created spaces" or alternatively to work with community members to bring new spaces for engagement into existence.

Is your understanding of "the community" sufficiently diverse and broad?

A second issue to consider when thinking about community engagement relates to the diversity and breadth of the people identified for community engagement and involvement. Too often CEI in global health research defaults to working with established community gatekeepers and local leaders who can facilitate the initial stages of an engagement process. In doing so, the engagement and involvement component of the overarching research programme can inadvertently skew in the direction of those within a given community that have more power and social capital than others. One way to avoid defaulting to a recruitment checklist approach (for example, loading up a focus group with a certain number of men, women, older people, younger people, people with disabilities, people of distinct socio-economic or education status) is to begin the community engagement process by considering: ***will a range of community members be engaged, including those considered disadvantaged, lower status, or marginalised within the community?*** To ensure that the powerful and/or those who typically have a voice in health research do not dominate decision-making by force of numbers, it is essential to ask: ***will the number of community organisation staff and community members participating in decision making be greater or equal to academic partner staff [3]?***

This people-centred approach also requires attentiveness to the limitations of the community groups or organisations you are working with in terms of their own prejudices or practices of exclusion. The extent to which a given community organisation is inclusive should not be taken for granted. Some consideration should go towards learning more about who is represented in their organisation and who is able to raise their voice and be heard within deliberative processes, and who is not. Given that unequal relationships of power exist within research collaborations, within communities, and in the spaces and sites where researchers and communities meet, it is important to take into account the potential need for separate consultative processes so that marginalised individuals have the opportunity to contribute without fear of social reprisal or negative repercussions. The idea is to create spaces of "comfort" where people feel they can express as freely as possible their perspectives on the research agenda, its implementation practices, and the analysis of research outcomes [9-10].

What does “the community” get in exchange for their giving of time, resources, connections and knowledge?

There has long been an implicit assumption in global health research interventions that because “communities” are potentially beneficiaries of improved health service delivery, targeted disease-prevention or treatment interventions, or health worker capacity-building, that they are not entitled to further benefits as a result of their participation. Similarly, a given community may have unrealistic expectations of what benefits they might receive given past experience with development and health interventions, or not know the specifics of funding restrictions. As with all aspects of community engagement, the most important element is honest and open dialogue and setting realistic expectations for what a given project can deliver.

For those community partners who play a participatory or peer research role, or who are actively involved in recruiting further participants, you may wish to think about how you can formally contract them (and pay them) as part of the local research team. For other issues of compensation, it depends on the specific cultural context in which you are working (in some instances, direct payment may be considered disrespectful and can create unintended tensions at local level). Thus, it is important to have a consultative process in the initial stages of the engagement to work out what constitutes meaningful forms of reciprocity that researchers can offer as part of a time-bound project [11]. Specific to the question of financial reimbursement, NIHR offers the following guidance.

Community leaders interview providers in rural healthcare facilities in Totonicapan and Sololá provinces, Guatemala. © CEGSS, Guatemala. All rights reserved.

Ethical dilemmas for community engagement and involvement in the context of the Covid-19 pandemic

Having covered both here, and in previous learning resources, good practices and critical reflections to guide the design of an NIHR-fundable CEI approach, we come to the ethical challenges posed by Covid-19 [12-13]. Where previous practices of CEI revolved around face-to-face meetings and the kind of relationship building best done in person and over time, Covid-19 meant that CEI practitioners had to rapidly pivot towards different ways of working [14-15]. This raised some important, as yet open-ended questions about who to engage, how to engage, what to engage about (Covid-19 relevant information or one's own research questions), what to do to protect both research team members and communities from harm, and how to reach the digitally excluded.

There are numerous challenges raised by doing CEI in the context of the Covid-19 pandemic, but a few guiding questions may help to begin addressing them. We start with three:

1. Where there are restrictions on movement and face-to-face meetings, how might you prioritise which community members or which communities to engage with?
2. What might you do to ensure staff and community members are safe and feel supported when resuming face-to-face engagement activities? If safety remains a concern, or you anticipate further Covid-19 infection spikes that would preclude face-to-face interaction, what contingencies might you put into place to enable CEI activities?
3. What other methods might you use to reach the vulnerable and marginalised groups or individuals within the communities where you work, taking into account differential access to mobile phones and internet, or other barriers to using virtual communication methods?

The primary concern here is to ensure that, even with restrictions or different ways of working in place, that CEI efforts are still attentive to the power dynamics and experiences of exclusion and vulnerability that operate at community level. This might require a re-mapping of key stakeholders and relationships of power and influence relevant to your planned research that have been changed as a result of the social and economic impacts of Covid-19.

Clear and timely communication, expectations management, and honest conversations with community members has proved even more important in the aftermath of Covid-19, particularly in light of the health infodemic. It is all the more crucial that CEI processes are attentive to changed expectations in light of urgent health needs, and where expectations cannot be met, that research teams look for opportunities to broker relationships between local communities and those with the power and resources to address these needs.

Committing to doing CEI ethically: building forward better

Covid-19 has drawn public attention to the 'strong association between race, ethnicity, culture, socioeconomic status and health outcomes' and raised awareness of health inequities [16]. A social justice approach to community engagement and involvement in research must foreground ethical considerations. While an individual health research project cannot address systemic and structural disparities that contribute to ill-health, a meaningful CEI approach can be attentive to the lived experiences of marginalisation and exclusion.

The list of resources provided here offer ample opportunity to learn more about current ethics debates in global health research, as well as tool kits and guides that can aid the planning and design of your proposed work. There is no model approach or "right" way to do CEI. What there is instead is an opportunity to push at the boundaries of what is possible to achieve in terms of power-sharing and co-production in health research, and an opportunity to be challenged in your own thinking and biases along the way.

Author info:

Erica Nelson works in a range of overlapping fields that include health policy and systems research, accountability for health equity, critical histories of global health and participatory research approaches in contemporary health research interventions. She is based at the Institute of Development Studies.

Bridget Pratt is an ethics researcher and the Senior Lecturer in Healthcare Ethics at the Queensland Bioethics Centre at Australian Catholic University in Brisbane. She is a Visiting Professor at the Julius Centre for Global Health at Utrecht University in the Netherlands. She has developed a toolkit for Sharing Power with Communities in Priority-Setting for Health Research Projects, which is freely available on her website - researchforhealthjustice.com .

Dorcas Kamuya is the current Head of the Health Systems and Research Ethics (HSRE) Department at the KEMRI-Wellcome Trust Research Programme. She is a social science researcher in LMIC contexts, with a focus on: ethical and social-cultural issues around emerging technologies (biobanking, machine learning); the value of community and public engagement in health research; ethical dilemmas for frontline research workers; and responsibility of researchers and research institutions conducting research in resource-limited contexts.

Noni Mumba heads the Community Engagement Platform at the KEMRI Wellcome Trust Research Programme (KWTRP). She has a background in Health and Strategic Behaviour Change Communication, Social Marketing and more recently Science Communication. Her primary work involves developing best practice strategies for the involvement of communities and publics in research initiatives across distinct KWTRP sites.

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Additional Resources

There are a range of useful web-based resources that expand on the issues briefly outlined here, which we recommend as starting points to more deeply reflect on how to embed ethical considerations into a dynamic practice of community engagement and involvement. Far beyond the references cited above, these sites include extensive bibliographies on the topics of social justice and health equity in global health, on ethical best practice in community engagement and involvement, and on ethics issues more broadly in the context of global health research collaborations.

https://www.researchforhealthjustice.com

https://www.researchforhealthjustice.com/r4hj-framework

https://healthsystemsglobal.org/thematic-groups/ethics/

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